Research Article

RESILIENCE AMONG PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

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Abstract

Introduction: Autism falls under the most common category of the Pervasive Developmental Disorders (PDD). It is a lifelong neurodevelopmental disability characterized by persistent and pervasive impairments in social understanding and communication, poor adaptive functioning, and the presence of restricted or repetitive behaviors and interests. Worldwide, caregivers find caring for children with Autism Spectrum Disorder (ASD) challenging. Learning how to become resilient may help family members overcome the stress and burden associated with caring for a person with ASD. Objective: To assess the pattern of resilience among the parents of children with autism spectrum disorder and to measure the association of pattern of resilience with selected background variables. Methods: A descriptive cross sectional, questionnaire-based survey was carried out among 174 parents of children with ASD in selected autism care centers of Kathmandu, Nepal. The data was collected using Connor-Davidson Resilience Scale 25 (CD-RISC-25). Both descriptive (frequency, percentage) and inferential statistics (Chi-square test) were used to analyze data in SPSS vs20. Results: The findings of the study revealed, majority of the respondents were below 35 years of age (70.1%), female (55.2%), belonged from Brahmin/Chhetri (63.2%) ethnic group, had a single child (62.1%), belonged to nuclear family (52.9%), were homemakers (34.5%), able to spend sufficiently economically (66.7%) and having a graduate or higher education (71.3%). Similarly, majority of autistic children were aged between 1 to 5 years (93.1%), and were males (71.3%). In terms of birth order, the majority of children with autism were the first-borns (72.4%), did not have any other illnesses (96.6%) and were diagnosed at the age of less than 3 years (62.1%). Overall, majority (59.7%) of the respondents had intermediate level while the remaining (40.3%) had highest level of resilience. Likewise, there was significant association of the level of resilience with ethnicity of respondents ($p=0.015$, $p<0.05$), occupation ($p=0.007$, $p<0.05$) of respondents, education level of respondents ($p=0.000$, $p<0.05$) and their spouses ($p=0.000$, $p<0.05$).

Keywords: Brain death, Organ donor, Organ harvesting, Transplant, Trauma.

INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disability characterized by persistent and pervasive impairments in social understanding and communication, poor adaptive functioning, and the presence of restricted or repetitive behaviors and interests. [1] Autism falls under the most common category of the Pervasive Developmental Disorders (PDD).Autism can affect any child of any family irrespective of racial, ethnic, or social boundaries; economic status; lifestyle choices; or educational levels.The authentic estimation of autistic person's population in Nepal is still a challenge as many people are unaware about it with very weak diagnosis. About 250000-300000 persons are estimated to be diagnosed with Autism (PWAs) in Nepal of which the number of severely affected ones ranges between 60,000-90,000.[2] Parenting is a challenging job and can be stressful as well. But then, the intensity of that stress is aggravated when it comes to parenting children with special needs.[3]An impact on the level of parental distress can be evaluated being based on parental coping styles and the presence of social support in relation to developmental disabilities.[4] Family resilience is considered to be used as a growing field of inquiry/investigating factors, the contribution of which is directly proportional to family's becoming stronger despite the adversity.[5] In order to overcome the stress and burden associated with caring a person with ASD, it is inevitable to learn resilient techniques.[6]

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The management of many aspects of caregiving is a compulsion to family members despite of it being demanding, overwhelming with a possible effect on family members' mental health.[7]A qualitative study revealed the finding which indicated social support, spousal relationship, and family time, togetherness and routines as being the most significant resilience-promoting factors with ASD. While for important resilience resources- family hardiness, family problem-solving communication, and family time and routines were considered the genuine one.[8] The significance of resilience can be reflected in various examples one of which could be the improvement in parents' problem-solving ability and development of their ability to actively and positively cope with stress.[9] Worldwide, caregivers find caring for children with Autism Spectrum Disorder (ASD) challenging. Family members must manage many aspects of care giving, which is demanding, overwhelming, and can affect the family members' mental health.[6]Resilience is a protective factor against psychological distress in adverse situations involving loss or trauma. It can help in the management of stress levels and depressive symptoms. Psychological resilience refers to the mental fortitude to handle challenges and adversity.[10] Autism is also common in Nepal. But studies related to autism are scant. The first article published on Autism reported that there is a lack of knowledge and awareness among parents and professionals regarding autism in Nepal.[11] Nepal is one of the low-income countries where the infrastructure for health services and education is limited. In Nepal, there are few organizations addressing and helping autistic children and their parents. So, it can be concluded that there is a great need for narrating and understanding the experience of parents with

autistic children to address the inadequacies in health, education, and social systems[12].There has been relatively less research conducted in Nepal regarding resilience among parents of children with autism spectrum disorder, therefore this study aims to assess the resilience among those parents in Kathmandu, Nepal.

MATERIALS AND METHODS

A descriptive cross sectional study design was adopted for the study. The study was carried out among the parents of children diagnosed with autism spectrum disorders from autism care centers of Kathmandu, Nepal, selected using non probability convenience sampling method. The sample size for the study was calculated by using the formula for infinite population as there is no reliable estimates mentioning the statistics of people with autism in Nepal with the following assumptions: z being 1.96, p being 50%, a 5% margin of error. The calculated sample size was 422 after adding 10 percent non response rate. Ethical approval was obtained from ethical review board of Nepal i.e. Nepal Health Research Council (NHRC) (Ref. No. 2771) to conduct the study. Written informed consent was taken from the participants prior to the administration of questionnaire. Data was collected from May 2023 to August 2023 by using self-administered questionnaire which consisted of 2 sections, prepared after the review of relevant literatures.

Section 1

Consisted of Demographic proforma which assessed demographical characteristics of parents: age, sex, ethnicity, education of parents, occupation of parents, economic status, type of family, number of children, number of children with autism. It also assessed child characteristics: current age, gender, birth order, age at diagnosis, ASD spectrum, comorbidity and duration of training in autism centers.

Section 2

Consisted of Connor-Davidson Resilience Scale 25 (CD-RISC-25) that was used to measure the pattern of resilience among the parents. It was developed by Kathryn M. Connor and Jonathan R.T. Davidson as a means of assessing resilience. Permission was obtained from the author to use the scale. It consists of 25 items rated as not true at all, rarely true, sometimes true, often true and true nearly all the time. Each item ranges in score from 0 to 4. The total score is obtained by adding up all the 25 items, which gives a score that can range from 0 to 100. Resilience was categorized as Lowest score: 1-25%, Intermediate score: 26-75% and Highest score: 76-100%. Lower scores indicate less resilience and higher scores indicate greater resilience.[13] The collected data were entered, cleaned and analyzed in SPSS (Statistical Package for Social Sciences) version20. Descriptive statistics including frequency and percentage was used to analyze the data and association of resilience with socio-demographic characteristics was assessed by using Chi-square test.

RESULTS

Table 1 presents the socio-demographic details of 174 respondents of autistic children. Among them, majority of them were below 35 years of age (70.1%), female (55.2%) and belonged from Brahmin/Chhetri (63.2%) ethnic group. Also, most the respondents had a single child (62.1%), belonged to nuclear family (52.9%), were homemakers (34.5%), able to spend sufficiently economically and highly educated with 71.3% having a graduate or higher education.

Table 1. Socio-demographic Characteristics of Respondents

n=174

Indicators	Frequency (N=174)	Percent(%)
Age category		
< 35 years	122	70.1
≥35 years	52	29.9
Sex		
Male	78	44.8
Female	96	55.2
Ethnicity		
Dalit	4	2.3
Janajati	48	27.6
Madhesi	8	4.6
Muslim	4	2.3
Brahmin/Chhetri	110	63.2
Number of Children		
1	108	62.1
>1	66	37.9
Family Type		
Nuclear	92	52.9
Joint	82	47.1
Occupation		
Homemaker	60	34.5
Self employed	56	32.2
Government employee	20	11.5
Private employee	32	18.4
Agriculture	6	3.4
Education Level		
Read & write only	2	1.1
Secondary level	10	5.7
Higher secondary level	38	21.8
Graduate and above	124	71.3
Economic Status		
Sufficient to spend	116	66.7
Insufficient to spend	44	25.3
Sufficient to save	14	8.0

Table 2 displays the socio-demographic distribution of children with autism. The majority of autistic children were aged between 1 to 5 years (93.1%) and were male (71.3%). In terms of birth order, the majority of children with autism were the first-born (72.4%), did not have any other illnesses (96.6%) and were diagnosed at the age of less than 3 years (62.1%).

Table 2. Respondents' Child Characteristics

n=174

Indicators	Frequency	Percent(%)
Age(in years)		
1 to 5	162	93.1
6 to 10	12	6.9
Sex		
Male	124	71.3
Female	50	28.7
Birth Order		
1st child	126	72.4
2nd child	46	26.4
4th child	2	1.1
Other Illness		
Yes	6	3.4
No	168	96.6
Diagnosed Age		
<3 Years	108	62.1
3 to 5 years	66	37.9

As presented in Table 3, majority (59.7%) of the respondents had intermediate level and the remaining had highest level of resilience. Meanwhile, none of the respondents had low level of resilience. Data presented in Table 4 showed that there was significant association of the level of resilience with ethnicity of respondents (p=0.015, p<0.05), occupation (p=0.007,

p<0.05) of respondents, education level of respondents (p=0.000, p<0.05) and their spouses (p=0.000, p<o.05) as well.

Table 3. Respondents' Pattern of Resilience

Resilience Score	Frequency	Percent(%)
Low (1-25%)	0	0
Intermediate (26-75%)	104	59.7
Highest (76-100%)	70	40.3

Table 4. Association of Resilience with Socio-demographic Characteristics

n=174

Indicators	Intermediate Score (26-75)	Highest Score (76-100)	P-Value
Age			0.086
< 35 years	78(75.0%)	44(62.9%)	
≥35 years	26(25.0%)	26(37.1%)	
Sex			0.151
Male	42(40.4%)	36(51.4%)	
Female	62(59.6%)	34(48.6%)	
Ethnicity			0.015*
Dalit	2(1.9%)	2(2.9%)	
Janajati	22(21.2%)	26(37.1%)	
Madhesi	8(7.7%)	0(0.0%)	
Muslim	4(3.8%)	0(0.0%)	
Brahmin/Chhetri	68(65.4%)	42(60.0%)	
Number of Child			0.272
1	68(65.4%)	40(57.1%)	
>1	36(34.6%)	30(42.9%)	
Education level			0.000*
Able to read and write	0(0.0%)	2(2.9%)	
Secondary	0(0.0%)	10(14.3%)	
Higher Secondary	18(17.3%)	20(28.6%)	
Graduate and Above	86(82.7%)	38(54.3%)	
Education level of spouse			0.000*
Primary level	0(0.0%)	2(2.9%)	
Secondary level	6(5.8%)	4(5.7%)	
Higher secondary level	20(19.2%)	38(54.3%)	
Graduate and above	78(75.0%)	26(37.1%)	
Type of family			0.754
Nuclear	56(53.8%)	36(51.4%)	
Joint	48(46.2%)	34(48.6%)	
Occupation			0.007*
Homemaker	36(34.6%)	24(34.3%)	
Self employed	34(32.7%)	22(31.4%)	
Government employee	16(15.4%)	4(5.7%)	
Private employee	12(11.5%)	20(28.6%)	
Agriculture	6(5.8%)	0(0.0%)	
Occupation of Spouse			0.157
Homemaker	26(25.0%)	22(31.4%)	
Self-employed	32(30.8%)	26(37.1%)	
Government employee	12(11.5%)	2(2.9%)	
Private employee	22(21.2%)	10(14.3%)	
Agriculture	8(7.7%)	4(5.7%)	
Foreign Employment	4(3.8%)	6(8.6%)	
Economic Status			0.968
Sufficient to Spend	70(67.3%)	46(65.7%)	
Insufficient to spend	26(25.0%)	18(25.7%)	
Sufficient to save	8(7.7%)	6(8.6%)	
Level of Autism			0.088
Mild	68(65.4%)	40(57.1%)	
Moderate	32(30.8%)	30(42.9%)	
Severe	4(3.8%)	0(0.0%)	
Family History of Autism			0.726
No	4(3.8%)	2(2.9%)	
Yes	100(96.2%)	68(97.1%)	

Chi-Square Test
*Significant at p-value < 0.05

DISCUSSION

Of the total 174 respondents, the findings revealed that majority of them were below 35 years of age (70.1%), female (55.2%) and belonged from Brahmin/Chhetri (63.2%) ethnic group. Also, most the respondents had a single child (62.1%), belonged to nuclear family (52.9%), were homemakers (34.5%), able to spend sufficiently economically and highly educated with 71.3% having a graduate or higher education. Overall, it was observed that majority (59.7%) of the respondents had intermediate level and the remaining had highest level of resilience. Meanwhile, none of the respondents had low level of resilience. The present study findings are in contrast to the findings of a study by Al-Jadiri et al[15] which showed low resilience in 32% of families. Low family resilience was significantly associated with parent factors such as not having someone to turn to for support, cutting work hours, and feeling "child hard to care for"; child ASD-related factors such as moderate ASD severity; and health care factors such as lack of satisfaction in communications with providers. Similarly, the present study showed that there was significant association of the level of resilience of parents with their ethnicity, occupation, education level of both the respondents and their spouses. These findings are again in contrast with the findings of the same study[15] which revealed that there were no significant differences in sociodemographic factors in high-versus low-resilience groups among families of children with ASD. However, in line with the findings of the present study, a study by Sinha et al[14] revealed that resilience scores did not differ across parental gender, gender of the child, diagnosis of the child, family type or socio-economic status, parental education and parental occupation. Likewise, the current study showed no significant association of child ASD related factors with the parents' level of resilience. These findings are contradictory with the findings of the study[14] which showed that Child ASD-related variables such as moderate ASD (by parent report) were more likely to be in the low-resilience group (42%) versus mild ASD (24%) or severe ASD (28%; p ≤ 0.01). There were no significant differences in likelihood of low resilience based on whether the child received behavioral or medication treatment for ASD.

Conclusion

Based on the findings of the present study, it can be concluded that the majority of participating parents had intermediate level of resilience from Nepal which indicates that parents need to improve their level of resilience. Furthermore, the findings suggest that there was significant association of the level of resilience of parents with their ethnicity, occupation, education level both the respondents and their spouses as well. Learning how to become resilient may help family members overcome the stress and burden associated with caring for a person with ASD. It can help in the management of stress levels and depressive symptoms. Parents of children with ASD who possess indicators of resilience are better able to manage the adversity associated with caring for children with ASD. Thus, enhancing resilience among family members of persons with autism may be beneficial to both the caregivers and care recipients. Interventions on the part of community leaders, political leaders and mental health professionals may be necessary to bring needed improvement in the pattern of resilience of parents. Further research is necessary to evaluate the effectiveness of various programs that help parents become more resilient.

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